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Review article

The ephemeral self: The legitimacy of an advance euthanasia directive

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Abstract

It is hard to say at what point someone with dementia has changed so dramatically that the self that existed before the dementia manifested itself cannot be said to exist (anymore). This issue raises important existential questions and may call into question the validity of a living will, in particular that of an advance euthanasia directive. The idea that the request expressed in such a directive should always be respected, regardless of conflicting expressions by the severely demented individual, may conflict with the interests of that individual. Balancing the various interests is the difficult task undertaken in this paper.

Keywords

Euthanasia, advance directive, dementia, self, personhood

Introduction

As a country's population ages, afflictions that affect the elderly in particular become ever more problematic, among which dementia, mainly caused by Alzheimer's disease, is a growing concern.

This paper discusses an existential issue with which many people who are diagnosed with dementia are confronted. They wonder how long they will remain the same person they are now and what it would be like to live as a (severely) demented individual. These are no mere academic questions, and practical philosophy, particularly medical ethics, is the next domain to explore. Someone who fears the existence with (severe) dementia may wish to ensure that certain health care decisions will be made if he is, as a demented individual, no longer able to make them, to which end a living will may be written. A specific sort of living will, namely, the advance euthanasia directive, features prominently in this paper. The main question to be answered is whether an advance euthanasia directive must always be respected, regardless of certain interests the severely demented individual may have of its own.

The section 'The status of a person with dementia' explores the position of someone with severe dementia. I inquire whether and, if so, in what sense such an individual is to be deemed a person, and whether the self that may (still) be said to exist is to be qualified as a continuation of the self that existed before (severe) dementia set in. Section 'The living will in the form of an advance euthanasia directive' discusses the advance euthanasia directive, which is no merely academic issue, since performing euthanasia on an individual with dementia is allowed in the Netherlands, provided that strict criteria are observed.

Section 'The decision to respect the directive' brings together the findings of sections 'The status of a person with dementia' and 'The living will in the form of an advance euthanasia directive'. Which expression or expressions (if they conflict) should decide whether the advance euthanasia directive of someone who has become severely demented is to be respected? Before the individual became incompetent, he requested to have his life terminated in the case of (severe) dementia; does this mean that the request should override expressions from the (same) demented individual? A simple answer to this question is not to be expected, if only because of the difficulties involved in balancing the – conflicting – interests.

The status of a person with dementia

The standard person with dementia does not exist. First, several causes have been identified for dementia, notably Alzheimer's disease. Second, and more importantly for this paper, the symptoms of dementia manifest themselves over a number of stages, generally worsening as it progresses. Initially, one may merely experience intermittent memory loss, while the final stage can result in an individual that may, insofar as the 'inner' faculties are concerned, hardly be recognizable by those closest to him, leaving

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them, together with healthcare providers, to question to what extent such faculties are extant.

The import of this issue, both academically and practically, is clear, and the question whether someone who has become demented may be said to be the same individual as the individual that could be identified before dementia set in (see Menzel and Steinbock,[1] p.488) has engendered a debate that has become so voluminous that a special term has been coined to refer to it, having become known as the 'then-self versus now-self' problem (Miller et al.,[2] p.87); the fact that dementia is progressive and cannot, accordingly, be qualified in an all-or-nothing way does not simplify matters (Walsh,[3] p. 59). In that respect, one may point to (amongst other aspects) some cognitive continuity that may exist between the individual before dementia set in and the individual with dementia(see Battin and Kious,[4] p.43, 44).

That the significance of such considerations extends beyond the armchair some have designated their sole piece of furniture is demonstrated by the struggle physicians may experience in deciding whether to adhere to an advance directive and, more particularly, a living will. A living will is a species of an advance directive; it can specify what health care decisions should be made if one is no longer able to do so oneself. A number of important aspects of this issue will be discussed in the next section. A question that may preliminarily be raised is whether an advance directive may (and must) be respected. As DeGrazia observes:

> One concern about the use of advance directives is distinctively philosophical: the possibility that, in certain cases in which a patient undergoes massive psychological change, the individual who exists after such change is literally a (numerically) distinct individual from the person who completed the directive. If this is true, there is good reason to question the authority of the directive in question, since it is supposed to apply to the individual who completed it, not to someone else. This may be called 'the someone else problem'(see DeGrazia,[5] p.374).

Accordingly, DeGrazia maintains that '[…] the severely demented patient is someone else – someone other than the author of the directive' (see DeGrazia,[5] p. 379). An important element in his argumentation is the claim that a severely demented individual is not *another* person than the individual who wrote the advance directive, but not a person *at all*. (see DeGrazia,[5] p.379). This raises the related questions what the meaning of the term 'person' is and which beings may be said to be persons.

The passage in which Locke presents his view has become a veritable *locus classicus*. Locke[6] (p.333) defines a 'person' as '[…] a thinking intelligent being, that has reason and reflection, and can consider itself as itself, the same thinking thing in different times and places […]'. Korsgaard's[7] conception of rationality is intricate, as she, too, equates a person with a rational agent (p. 25) but considers the aspect of self-determination decisive (p.69). An individual with severe dementia does not appear to qualify as a person if rationality in this sense is the standard. This becomes all the more apparent from Korsgaard's (p.42) claim that '[…] what it is to be a person, or a rational agent, is just to be engaged in the activity of constantly making yourself into a person […]'.[7] It is difficult, incidentally, to grasp what this means, since someone is supposedly making himself into a person while apparently already being one (one may try to evade this problem by maintaining that one, already being a person, through one's actions evolves *as a person*, but such a 'solution' is insufficient to offset the obscurity that is expressed in a similar statement: '[…] we human beings constitute our own personal or practical identities – and at the same time our own agency – through action itself. We *make* ourselves the authors of our actions, by the way that we act' (see Korsgaard,[7] p. 45)), but that is a separate matter that does not have to be discussed here.

Korsgaard (p.214) holds that rational agents must act in accordance with a universal law, which '[…] has to be one that would enable you to maintain your integrity, in any situation, come what may'.[7] Difficultly, however, applied to the present issue, people have different views with respect to the (un)desirability of continuing living as a severely demented being; Korsgaard does speak of 'your integrity', but if the integrity refers to the 'you' that is still rational, what she says is circular from the point of view of someone who does not limit the designation of 'persons' to those who are rational.

To do justice to her position, it must be added that Korsgaard has a Kantian perspective, which aids in estimating what she says. From such a perspective, one may argue that a living will must be respected (Korsgaard holds that there is a duty to continue to act in accordance with a law one has made for oneself unless there is a good reason to change it (see Korsgaard,[7] p.202); a severely demented being is no longer able to produce such a reason, at least not as a person in the proposed sense) and even that a duty to end one's life exists if (severe) dementia is imminent. Still, strong arguments have been leveled against the claim that this duty may be derived from Kant's (p.609, 610) practical philosophy.[8]

Whatever specific meaning one attributes to 'rationality' (or 'reason'), it may be argued that severely demented beings have ceased to be rational. If rationality is indeed the decisive criterion to characterize a being as a 'person', one may consistently deny that such a being is a person (see Buchanan,[9] p. 283, 298, 299).

The idea that rationality is indeed the decisive criterion to deem someone a person is not universally accepted, though, and one may, for example, hold that 'Cognitive continuity is […] only part of what makes for the

maintenance of personal identity'. (see Battin and Kious,[4] p.43). One may resist the idea that personhood is reduceable to rationality, claiming that '[…] correctly understanding the person's story, so that we make the right moral decisions, entails that we understand the person' (see Hughes,[10] p.78). In the absence of rational, verbal or emotional communication, the body may play a role as a means to communicate with someone with dementia (see Hughes,[10] p.79).

Since 'personhood' may be defined in various ways, as has become apparent, and it seems unlikely that a consensus with respect to its meaning is forthcoming (Gordijn,[11] p.348), absent a definition evidently capturing the 'essence' of what it is to be a person, the best course of action seems to be to avoid attributing a special meaning to the word (or even any meaning at all), so that there would be no basis to treat persons and non-persons differently merely on account of the meaning of 'personhood'. Failing both such a definition – which I, for one, am unable to provide – and such a course of action, the quest to capture what it 'truly' means to be a person will continue unabated, its participants mistakenly thinking they are all involved in the same inquiry, being united only insofar as the futility of their enterprises is concerned. This does not mean, though, that 'person' and 'personhood' must fall into desuetude, even if only because the terms may profitably be used, as will be shown.

'Personhood' is not a concept qualifying something existing as such, waiting to be defined, such as a mountain before it is defined as a 'mountain'. Rather, it serves to *qualify* beings that do themselves, just like mountains, exist. Rational human beings, other human beings and (nonhuman) animals all exist, and may as such be defined, but which of them are considered persons depends on the conception of 'person' one is willing to accept.

I readily grant that one may disagree with respect to the contents of the other definitions just mentioned as well. Applied to the example just given, the demarcation between a hill and a mountain is arguably arbitrary. Still, the definition is at least based on something that can empirically be determined to exist (namely, the object one observes), which is not the case with 'person'. A complication with respect to 'human being' is that it may be said not to be a mere biological category (human beings in this sense, like mountains or hills, being empirically observable) but a political one as well, there being a political interest – of human beings themselves, by the way – to distinguish between human beings and other beings.

Still, the qualification of 'human being' cannot randomly be assigned to any being lest it lose its meaning, which would happen if 'human being' were an *exclusively* political concept, separated from the biological denomination *homo sapiens*. The possibility of randomly assigning a qualification *does* exist, by contrast, in the case of 'personhood'.

This is (further) illustrated by certain legal categories. An obvious category to mention here is that of the juridical person; corporations may be qualified as such. The personality is obviously created: juridical persons do not exist as such and are *a fortiori* unable to act in any way. Their personality is a legal fiction, and while they, as actually nonexisting entities, have to be represented by human beings, they may have rights and duties of their own. In addition, the category of the physical person (also known as the natural person) is distinguished; human beings may be (and commonly are) legally qualified as such.

Since human beings exist as such, it might be tempting to conclude that the physical person is not a legal creation (as is the juridical person), but such a conclusion would amount to a (category) mistake, since both the physical person and the juridical person are legal persons and thus legal creations; a human being is obviously no legal creation, but the legal 'layer' that is realized by qualifying a human being as a physical person (the physical person being a species of the genus legal person) is.

As became clear in the foregoing, where various conceptions of 'person' were presented (like 'rational agent'), 'person' may also be used in a non-legal sense. I have indicated what the problem with 'person' in that sense is, namely the very fact that various – competing – conceptions exist, none of which is evidently 'correct'. There is, however, no problem in using 'person' in a less ambitious sense, namely, insofar as the only motivation to use the word is to have a convenient term to refer to certain beings; in this sense, 'person' may denote any subset of beings, such as rational human beings, all human beings or (both human and nonhuman) animals.

I presume many people will equate 'person' in this sense with 'human being', for example, in the statement 'There is a person at the door for you', so that the addressee would be surprised to find an animal. Still, this equation is no more than a convention and it does not provide a cogent argument against equating 'person' with the nonspecific 'τόδε τι' ('this something') (see Aristotle,[12] p.1028a) that is, that to which one refers without specifying it. (In this sense, 'person' may be considered a synonym of 'individual', although one would use 'τόδε τις' ['this someone'] in this case. These notions are not value-laden.) 'Person' *in this sense* does not afford those who are considered persons any special status (legal or otherwise), with the corollary that being a person does not entail having certain rights or duties. Given the neutrality of this conception, one may refer to someone with (severe) dementia as a person.

A conception of 'person' that *does* imply a certain status (again, absent a definition that evidently captures the 'essence' of what it is to be a 'person', with the corollary that various – competing – conceptions will (continue to) exist, in accordance with the parallel views the supporters of those conceptions will presumably defend unabatedly)

is problematic, even if only because the issue is not just a merely academic one. The conception of 'personhood' one adopts easily confuses matters or, even worse, may be used as part of a spurious reasoning, but for the present discussion it need not be problematized (Toomey,[13] p.58, 61). As Gordijn puts it:

> […] the concept of the person can easily be used as a cover-up concept: Since there is no independent external criterion of demarcation of qualities that are and those that are not necessary conditions for personhood, a participant in an [*sic*] bioethical debate can simply choose a specific set of properties as being necessary for personhood in order to corroborate his own moral views (see Gordijn,[11] p.355).

An important idea has not yet been explored: the self. Locke equates 'self' with 'person' (see Locke,[6] p.340), and his criterion to identify a 'person' has (albeit in a somewhat diluted formulation) indeed been presented as the defining criterion for the 'self': 'let us define a *self* as a *being who is self-aware* in the sense of having some awareness of itself as a being persisting over time' (see DeGrazia,[5] p.382). The problem already pointed out with respect to 'person' is no less pertinent here: why would this definition, rather than an alternative one, capture the nature of the 'self'?

It would be unjustified to conclude the discussion here, though. The conception of 'self' is arguably more intricate than that of 'person'. It cannot outright be dismissed as non-existing, since it is not clear that it is, like 'legal person', a creation. On the other hand, its existence is not discovered with the same ease as that of a human being. In any event, the issue cannot be disregarded here, even if only since it is inquired in the context of topic of the living will of a person with dementia.

If the person before dementia set in is supposed to be a self, and the person with severe dementia a *different* self (forgoing the issue here at what point the dementia has progressed enough to recognize a different self), the difficulty is that one may also, albeit in a different sense, speak of a unified self, since the different selves, as they apparently do not exist as separate, independent entities, must be conceived to be supported (presumably, in such a conception, one after the other) in the same 'substrate' (presumably the body).

Such a theory leads to the same challenges that were observed with respect to 'personhood'. After all, one may question what the 'real' self – which must be identified in order to determine whether the living will is to be respected – is: the rational self (i.e. the person before he became severely demented), the self of the person that is severely demented, or the body as an encompassing whole? (Along the lines of what will be discussed in section 'The living will in the form of an advance euthanasia directive', *practically* it does not matter whether the 'real' self would be identified with the second self or the body.)

Alternatively, one might consider the existence of a 'substantial' self (possibly to be identified as the soul), serving as the substrate (instead of the body), so that three 'selves' would exist, the two non-substantial selves (the second succeeding the first) existing as aspects or manifestations of the substantial self, which might be conceived as something akin to *prima materia* (prime matter), for which *prima anima* might be an apt denomination. A benefit of this theory is that it does not rely on the body, which is an arguably arbitrary element, but this comes at a certain explanatory cost: the soul cannot simply be presumed to exist and the burden to prove that it in fact exists is considerable. Apart from that, this account has all signs of an artifice.

The difficulties just observed may be avoided by adopting a conception of 'self' in accordance with which it is not necessary to determine what its nature is, nor even whether a single self, which gradually changes, may be identified, or rather a succession of selves, in which case a change in a self leads to a new self, where the absence of a definitive answer to the question when a change is significant enough to recognize a new self would not pose a practical problem.

Irrespective of which of these viewpoints (so either the idea of a continually changing self or that of a succession of selves) one accepts, the changes with regard to the self must be taken seriously, so that it is not amiss to speak of an ephemeral self. Individuals continually change, but failing a criterion to specify which changes are essential and which, conversely, concern mere accidental aspects, a stable self cannot be identified. A change to an arguably accidental element as one's hair colour may affect the way in which the person in question whose self is concerned regards him- or herself: some individuals consider such a change a minor issue while others may deem the feature a constitutive part of who they are. Such a change cannot, then, generally be dismissed as irrelevant when deciding whether the self is affected. Likewise, it may be doubted whether and, if so, to what extent the self of a Christian who changes his mind (no pun) after discussing his beliefs with an atheist, becoming an adamant atheist himself, has changed.

This is no more than a possible perspective on the self, so that it does not rule out the possibility of an alternative. A conception according to which the self is conceived as an essence (whether one calls it, perhaps along the lines presented above, a soul or not) that is somehow impervious to changes in life that leave marks (in which case such marks must presumably be considered to be superficial, even if they can have a great impact for those who experience them) cannot summarily be dismissed, but only because those denying its existence would be faced with the same burden those who defend its presence need to

acknowledge; that not all of them do so does not derogate from this given.

The living will in the form of an advance euthanasia directive

Some relevant general issues that bear on the living will of someone with severe dementia were discussed in the previous section. In the Netherlands, an additional complication may present itself, since the Dutch legislation accepts the possibility of realizing the request expressed in a living will in the form of an advance euthanasia directive. Both active and passive euthanasia are allowed; passive euthanasia consists in discontinuing life-prolonging treatment, while active euthanasia requires an active role on the part of a physician, who terminates the individual's life. In the following, 'euthanasia' means active euthanasia.

Pursuant to article 293 of the Dutch Criminal Code, euthanasia performed by a physician is not punishable if the criteria specified in the Termination of Life on Request and Assisted Suicide Act (TLRAS) are observed, among which the demand that the physician must hold the conviction that the patient suffers, which suffering must be unbearable, with no prospect of improvement. Article 2, section 2, of the TLRAS specifies the conditions for an advance euthanasia directive, in which someone capable of reasonably estimating his interests may detail a request that his life be terminated by a physician in the situation in which he suffers unbearably and has lost the ability to express his will (and thus to request that euthanasia be per-formed at that time himself).

An important question that arises in the case of a demented person is whether the euthanasia is *voluntary*. Importantly, the individual must have the will to have his life terminated; in the absence of such a will (or any of the other criteria that apply), performing (putative) euthanasia is a criminal act. This will must of course exist at the time of writing the advance euthanasia directive, but that issue will not be explored here, as it is not relevant for the present discussion. The issue that is relevant, however, is whether the will still exists once the stage is reached in which the person in question is no longer able to express it, and by raising it, the practical consequences of what has been discussed in section 'The status of a person with dementia' become apparent.

In the case of a living will in which someone has indicated that he wants to be euthanized if he has become (severely) demented, no longer being able to make the request at that point, on account that he qualifies his – expected – suffering as a demented person as unbearable and with no prospect of improvement, the same criterion should presumably be applied as in the case of a negative advance directive, like a do-not-resuscitate order (DNR order). Without any knowledge of an individual's preferences, a physician who is confronted with a person in need of assistance would attempt to revive that person, but should there be a DNR order, the physician gains relevant knowledge: he is informed that the individual does not want to be revived.

The physician in this example cannot with certainty know whether the individual in question does not want to be revived at that moment – the individual may have changed his mind at some point after signing the DNR order (without, for whatever reason, having withdrawn it) – but must act on the basis of the (only) information at his disposal. Similarly, in the case of an advance euthanasia directive, if the demented individual is no longer able to express himself, the physician has no other information at his disposal than what is expressed in the advance euthanasia directive, perhaps, if he knew the individual at the time when he wrote the directive, supplemented by what the individual told him, which may aid him in interpreting the directive, if useful.

However, the practice of acting in accordance with an advance euthanasia directive in the case of a severely demented person is not as straightforward as this comparison suggests. This is illustrated by an important ruling by the Dutch Supreme Court, which concerned a physician who had, in accordance with an advance euthanasia directive, terminated the life of a severely demented person.

The Supreme Court considers that a patient's dementia is no impediment in respecting the will expressed in the directive.[1] The fact that dementia is at issue does not derogate from the demand that the criteria of unbearable suffering and suffering with no prospect of improvement must be observed.[2] The suffering itself may be physical (either – indirectly – caused by the dementia itself, such as pain resulting from bed sores, or not) or be identified as another situation that has been characterized in the directive as unbearable suffering, provided the demented person's persistent behaviour is such that one may infer that he is indeed experiencing unbearable suffering.[3]

Importantly, though, the directive may only be observed if the demented person is no longer able to express his will.[4] Absent signs that indicate actual suffering, the qualification in the directive of the (prospective) suffering is, in and of itself, insufficient to conclude that the demented person is indeed suffering.[5] In addition, indications that conflict with the request expressed in the directive, that is, contraindications, may bar the realization of the request. These may either be manifested in the period in which the person was still able to form and express his will or in the period after he has, due to the progression of dementia, become unable to do so. Contraindications of the latter sort cannot be interpreted as expressions of the person's will, intended on withdrawing or changing a previous request, but they do have to be taken into consideration in the assessment of the person's physical and mental condition, and may lead the treating physician to conclude that the situation that was

expected to occur and is as such expressed in the directive has not occurred.[6]

Given the fact that contraindications are not to be ignored, even if they are not considered expressions of the demented person's will, which may, insofar as something else than instinct is intended, at some stage perhaps be deemed merely fictitious, the demented person is apparently not treated as the material remnant of a former individual. Apart from the principal reasons that may be presented against performing euthanasia in such a situation, which will be discussed in the next section, one may maintain: 'It is hard to see […] how the physician can assess whether the patient's suffering is unbearable and hopeless and whether alternative solutions are available and acceptable' (see Hertogh et al.,[14] p.50).

So if the demented person does not exhibit (persistent) behaviour that signals unbearable suffering, the basis to perform euthanasia is lacking (see Widdershoven,[15] p.105,106). This conclusion may conflict with the request of the person who wrote the advance euthanasia directive. The present section has produced insufficient information to answer the question how the interests of the person who wrote the advance euthanasia directive and those of the severely demented person should be balanced; the final section is the place to confront this predicament.

The decision to respect the directive

A proper idea to explore in inquiring in what cases the directive should be respected is 'autonomy'. As Dworkin (p.221) asks: 'Does a competent person's right to autonomy include […] the power to dictate that life-prolonging treatment be denied him later, or that funds not be spent on maintaining him in great comfort, even if he, when demented, pleads for it?'[16]

'Autonomy' in the literal sense, so with the meaning of imposing a law on oneself, is notoriously difficult to grasp, inter alia because it is unclear on what level this action (supposedly) takes place; should someone consider himself somehow 'split' in the person as he may be observed and interacts with others and the being that imposes the law on that person? Kant (p.6), who takes seriously the difficulties in attempting to resolve this issue, rightly speaks of a paradox in this respect.[17] Even in the case of a person that does not suffer from dementia (or a similar affliction), then, the meaning of 'autonomy' is problematic.

'Legal autonomy' does not involve such conceptual concerns, and does not raise similar problems, at least not insofar as 'normal' persons, who may here be identified as competent persons, are concerned. Persons with severe dementia, however, are not deemed competent. Still, it seems unwarranted to outright dismiss such persons' autonomy on that basis, since it is not evident that losing competence is a sufficient condition for losing legal autonomy.

Dworkin (p.192) distinguishes between the autonomy of the person who became demented and the autonomy of the demented person,[16] thus acknowledging the autonomy of the latter. Importantly, however, two views of autonomy are at issue: the evidentiary view and the integrity view. The first view holds that all decisions are to be respected, even those deemed imprudent by others; since severely demented persons cannot know what is in their own best interests, they would not have the right of autonomy (see Dworkin,[16] p.223). Dworkin (p.224) dismisses this view in favour of the second, which aims to protect the capacity to express one's own character, encompassing not just experiential interests, but one's values, commitments and convictions.[16] Accordingly, a competent person's living will, testifying to his autonomy in accordance with the integrity view, is to be respected, even if the severely demented person's desires conflict with this outcome (see Dworkin,[16] p.226, 228).

Those who are severely demented may, being incompetent, be deemed no longer to be able to conduct legal transactions, in which case it may be justified to curtail their freedom in this respect. What is at stake here, however, is not the decision to conduct a legal transaction, such as buying a car. With respect to such an action, restricting the demented person's autonomy has the obvious purpose of protecting the interests of those who may be affected if it is not restricted. In cases where multilateral legal transactions are involved (such as in the example just mentioned of buying a car), the other party may determine that the demented person's mental capacities are impaired, so that no problem need arise (as long as the other party will not abuse the demented person's diminished capacity to its own advantage), but it may nonetheless be warranted to deem a demented person incompetent (and appoint a legal guardian).

This situation differs, however, from the right of a severely demented person to oppose euthanasia: no relevant interests of other parties are involved, apart from, for example, the interests of family members and, more abstractly, of society as a whole in reducing the costs of healthcare and housing facilities. Still, this consideration does not, in and of itself, provide a compelling reason to reject Dworkin's conception and its corollary. The interests of the severely demented person must be properly assessed, which requires an examination of these interests.

An important question to raise here is what suffering the demented person experiences. If he experiences suffering consistent with what has been specified in the living will, it may be respected, provided there is no conflicting overriding reason to reach a different conclusion. Since 'suffering' in general terms is too vague a standard to adhere to, one may demand that 'suffering with no prospect of improvement' and 'unbearable suffering' (which are, as was discussed in section 'The living will in the form of an advance euthanasia directive', important criteria in the

Dutch legislation to be allowed to perform euthanasia) must be apparent. This specification does leave something to be desired, but this is not the place to discuss it; fleeting suffering does not, in any event, seem to be a sufficient reason to perform euthanasia.

Failing continued suffering, there does not appear to be a prima facie reason to respect the living will. Still, a consideration may be that one does not want to continue to live in a state of dementia; the suffering would then be supposed to lie in the very given of being a demented individual, such suffering not being experienced by the demented individual himself, as he is presumably not even able to understand the import of the issue, but consisting, somewhat abstractly perhaps, in the idea that one will be remembered by others as that demented individual rather than as the individual one once was (see Buchanan,[9] p.286; Dworkin,[16] 287). This is a valid interest to take into consideration, but it must be balanced against the interests of the demented person.

It is difficult to assess what a severely demented person experiences, but one may at least presume that there is pain and pleasure. The pain is of course to be taken seriously, but with respect to the pleasure, one may hold that the person's only interest is '[…] having whatever fleeting, fragmentary, and unanticipated experiences of simple physical pleasure his or her damaged nervous system still allows' (see Buchanan,[9] p.286). In line with such a disparaging qualification of the demented person's interests, they may be deemed 'radically truncated'(see Buchanan,[9] p.286, 287, 299).

Dworkin's reasoning corresponds with this perspective. Dworkin (p.201) contrasts the experiential interests, which a severely demented person may have, with critical interests, namely, '[…] interests that it does make their life genuinely better to satisfy, interests they would be mistaken, and genuinely worse off, if they did not recognize'.[16] Balancing these types of interests, Dworkin[16] argues, in accordance with his emphasis on the importance of the integrity of the agent (see p.224), that the critical interests should prevail, considering the person's life as a whole, and the sort of person to which it testifies (see p.236, 237). Dworkin appeals to 'dignity', 'moral standing' and 'intrinsic' value; it may be questioned whether an appeal to such notions may be justified, but the scope of such an inquiry would be so great that it cannot be accommodated here (see Doomen,[18] pp.88-92).

It may be questioned whether accounts such as Buchanan's and Dworkin's do justice to the interests of persons with severe dementia. As Byers (p.36), who points to the need of taking seriously short-term well-being, puts it, 'Individuals' short-term well-being is valuable in its own right and a morally relevant factor in decisions that concern them, irrespective of whether they are living with dementia'.[19] Adopting such a perspective would necessitate reconsidering the importance of the experiential interests.

Is it possible, even if the analysis is restricted to pain and pleasure, to determine what life looks like for a severely demented person? It is difficult enough to put oneself, as a 'normal' person, in the place of another 'normal' person, with whom one can communicate, so this problem presents itself *a fortiori* in the case of a severely demented person. In a similar vein, Walsh (p.59) stresses the problem of assigning '[…] a subjective value to an experience, like dementia, which is epistemically inaccessible to you from your current standpoint'.[3] Accordingly, Walsh[3] (p. 62) rejects the contention that the preferences of a person with severe dementia may simply be dismissed.[3]

Related to this point, it may be difficult to imagine what it would be like to be demented oneself (regardless of one's stance with respect to the 'then-self vs. now-self' problem), just like it may be difficult for someone who is able to walk to imagine how he would experience being permanently confined to a wheelchair (see Wolff,[20] p.502, 503).

In addition, the case of severe dementia brings with it the particular issue that someone afflicted with it is not – in contradistinction to someone permanently confined to a wheelchair, provided that he is not also seriously cognitively impaired – aware of his condition, which may affect the extent to which suffering may be said to take place. This does not mean, of course, that suffering is absent (and, as has been discussed, severely demented persons may experience pain), but psychological research does show: 'While people experience a drop in subjective well-being upon becoming disabled, within a relatively short period of time they often regain the level of happiness they had previously' (see Menzel and Steinbock,[1] p.487).

The differences between the views with respect to the question of how the interests of severely demented person should be valued, in particular if the interests of the person before the dementia set in are also to be taken into consideration, do not make it easy to present an answer that will convince every party.

It does not seem inapposite to regard a severely demented person as a child that has become permanently cognitively impaired, terminally ill and experiences the same pain and pleasure as such a person. In the case of such a child, its parent(s), as its natural guardians, may, as a rule, make crucial decisions on its behalf; in their absence, a legal guardian may be appointed. The guardian may, given that a negative advance directive does not exist, decide that no life-prolonging treatment will be given.

Importantly, this analysis applies to a *negative* advance directive. With respect to an advance *euthanasia* directive, the situation is less straightforward. (For completeness I remark here that euthanasia on infants is permitted in the Netherlands, but only if stringent criteria are observed, in which case the physicians involved will not be prosecuted. In addition, the given that the distinction between active and passive euthanasia is not straightforward [see Rachels,[21] pp.78-80] admittedly complicates the issue.) In the first

case, the demented person will die, having fruitlessly been consulted about the possibility of withholding treatment, so that the only remaining basis for a decision is the directive. In the second case, by contrast, the request expressed in the directive rivals with the opposition manifested by the behaviour of the demented person, at least if such behaviour is indeed exhibited.

In the case of an advance directive, the person before the dementia set in either – if one considers the severely demented person a new self, possibly one in a long set of selves that have preceded it – serves as the severely demented person's (fictitious) guardian or – if one thinks a *single* self that has changed dramatically is at issue – must be taken to speak for himself by means of the directive, now that he is no longer actually able to do so. Practically, which of these conceptions of the (ephemeral) self one accepts is not relevant. What is practically relevant, of course, is which expression is deemed decisive.

The answer to this question depends on the answer one would provide in the case of the permanently cognitively impaired child mentioned above. If expressions by the child that may be interpreted as contraindications (in the sense indicated in section 'The living will in the form of an advance euthanasia directive') are to be respected (so that euthanasia would be deemed unacceptable in such a case), then the same conclusion must be reached in the case of a severely demented person. Conversely, should euthanasia in the first case be deemed acceptable, there is no principal reason to reject it in the second.

Once the severely demented person is no longer able to express himself in any way indicative of opposition to euthanasia, no obstacle to perform it remains (provided that all criteria for euthanasia are met), since this case does not qualitatively differ from one in which a physician acts in accordance with a negative advance directive. No basis to act one way or the other exists save for what is specified in the advance euthanasia directive, which is, accordingly, to be respected.

One may object, though, along the lines of what Dworkin and Buchanan argue, that the cases of a severely demented person and a permanently cognitively impaired terminally ill child differ in (at least) one important respect: while someone may not want to be remembered as a person who has become demented, this is not a consideration in the case of the child. Only if this interest is deemed important enough to override the interest of the demented person to stay alive is the directive to be respected.

An argument in favour of the alternative is that the severely demented person has no means to affect the position he is in, while the person who is on his way of becoming severely demented may, apart from committing suicide, request euthanasia in the interval between the diagnosis and the moment (which would be hard to indicate) he has become severely demented, so as long as he is still competent, a possibility the Dutch law allows. A problem with this option is that someone who wants to live as long as possible before becoming severely demented may have difficulties timing his request in the transitional period, ensuring that it is made before he is no longer (coherently) able to make it.

The more interests one considers, the more difficult this already challenging discussion becomes. Forgoing some of those that may clearly not be dismissed as trivial is not an option, though, if one's goal is to produce a contribution that captures all aspects of what is at stake.

Conclusion

The question what it means to be a self does not require a definitive answer in order to make sense of the main issue discussed in this paper, namely, in which cases an advance euthanasia directive must be respected. Such an answer has not been provided in this paper, which has made use of the fact that judgment can be suspended with regard to that metaphysical issue, focusing instead on the continuity between either the selves or the different manifestations of the same self; both conceptions of the self are compatible with what has been argued here, and both capture what it means to be an ephemeral self.

Being disburdened from the duty to present a detailed – and universally acceptable – conception of the self, I have instead discussed the status of the advance euthanasia directive in the case of individuals with severe dementia. Presuming euthanasia is considered acceptable in the first place, there does not seem to be a problem in allowing euthanasia to be performed in cases where the individual suffers unbearably, in accordance with what has been specified in the directive, once the demented individual is not able to express himself anymore, for nothing stands in the way of executing the directive; presuming that the demented individual disagrees with that outcome is as unwarranted as the contrary, namely, that he has a will that accords with it.

If he is, however, still able to express himself, however inarticulately and imprecisely, and his expressions amount to indications that conflict with the request expressed in the directive, outright dismissing his interests is unwarranted.

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Notes

1. Dutch Supreme Court, 21 April 2020, par. 4.3.1.
2. Dutch Supreme Court, 21 April 2020, par. 4.6.1.
3. Dutch Supreme Court, 21 April 2020, par. 4.5.2 and 4.6.2.
4. Dutch Supreme Court, 21 April 2020, par. 4.3.2.
5. Dutch Supreme Court, 21 April 2020, par. 4.6.3.
6. Dutch Supreme Court, 21 April 2020, par. 4.5.3.

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